



STATE OF WASHINGTON
WASHINGTON STATE BOARD OF HEALTH

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November 9, 2005

TO: Washington State Board of Health Members

FROM: Kim Marie Thorburn, MD, MPH, Chair

SUBJECT: POTENTIAL CHANGES TO HIV REPORTING RULE

Background and Summary

The Ryan White Act provides federal funding through the Health Resources and Services Administration (HRSA) for state and local programs that provide services to people living with the human immunodeficiency virus (HIV). HRSA allocates funds based on the number of cases in each state. The states provide surveillance data to the Centers for Disease Control and Prevention (CDC), which then provides data to HRSA. Prior to 2000, HRSA based its allocation on the number of acquired immune deficiency syndrome (AIDS) cases. The 2000 Ryan White reauthorization act changed this; the allocation is now based on the numbers of people living with HIV.

The State Board of Health has authority under RCW 43.20.050 to make rules for the control of communicable diseases, and this authority is the basis for the communicable disease reporting requirements contained in Chapter 246-101 WAC. In 1999, largely in anticipation of the Ryan White reauthorization act, the Board mandated reporting of HIV in addition to AIDS. Although AIDS cases were already reported by name, the idea that the state government would keep records of people with HIV raised concerns about potential privacy violations that could lead to stigmatization and discrimination. Facing one of the most contentious issues in its recent history, the Board ultimately settled on a compromise—it mandated reporting of HIV cases by name, but it also required that those names be converted to code—a unique identifier number—within 90 days.

Since 1999, CDC policy has urged name retention. Names are not reported to the CDC, but the federal government believes that keeping names on file is the best way to prevent duplication and avoid over-reporting of surveillance data. In past years, however, it has signaled a willingness to work with the 14 states, including Washington, that have adopted a name-to-code policy. That is no longer the case. Recent HRSA and CDC statements make it clear that beginning fiscal year 2007, they will no longer accept unnamed HIV case reports when allocating Ryan White dollars. That means the Board must quickly change its rule to allow confidential retention of the names of people with HIV or Washington State will very likely lose a significant portion of its Washington's Ryan White funds—potentially hundreds of thousands of dollars.

I have instructed Board staff to work with the Department of Health (DOH) to initiate rule making. A CR-101, Preproposal Statement of Inquiry, is being developed. I have asked Jack Jourden, Director of the DOH Division of Infectious Disease and Reproductive Health, to brief the Board on this issue. He will also address a proposal to change the type of HIV-related test results that laboratories must report. A memo from Mr. Jourden is attached, as are copies of recent statements from the CDC explaining that it will only accept data from states that have implemented name-based reporting.

Recommended Board Action

None.